

Supplementary material

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I. Supplementary Figures

Keto Case Series Study in ADPKD

Supplementary Figure 1

A

Online survey on eating habits and special diets in PKD patients
Collection of observational data using an online questionnaire

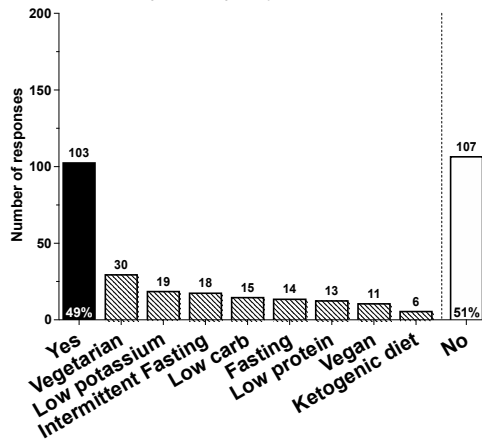


Study cohort „Eating habits“

Recruited by "Familiaere Zystennieren e.V." and
University Hospital of Cologne
N = 210 ADPKD patients

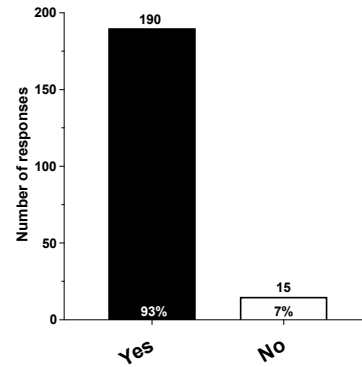
B

*Have you followed a specific diet so far ?
If so, please specify the kind of diet.*



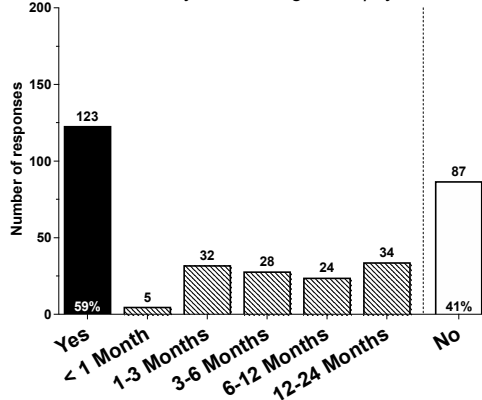
C

*Would you like to see more research
about nutrition in ADPKD ?*



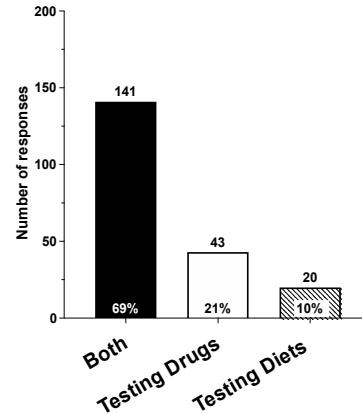
D

*Would you take part in clinical studies regarding
dietary interventions in ADPKD ? If so, for what
duration would you be willing to adapt your diet ?*



E

*In which area of research do you see
greatest need for new studies on ADPKD ?*



II. Supplementary Figure legends

Suppl. Figure 1. The interest of ADPKD patients in nutrition and diets

(A) PKD patients were recruited by the University Hospital of Cologne in collaboration with the German patient advocacy group “Familiaere Zystennieren e.V.” to participate in an online questionnaire about eating habits and special diets. (B) Participants were asked whether and what kind of specific diets they have followed so far. (C) Participants were asked if they would like to see more research about nutrition in ADPKD. N= 205. (D) Participants were asked if and for what duration they would take part in clinical studies regarding dietary interventions. (E) Participants were asked which area of research they see the greatest need for new studies in ADPKD. N=204.

III. Online survey about eating habits and special diets in ADPKD patients

Fragebogen Diät Zystennieren

Eine gesunde Ernährung ist inzwischen für viele Erkrankungen als wichtiger Bestandteil der Vorbeugung und Therapie anerkannt. Grundlagenwissenschaftlich haben sich in den letzten Jahren auch für die Zystennieren-Erkrankung starke Hinweise ergeben, dass bestimmte Ernährungsformen positive Auswirkungen haben können. Bislang fehlen hierzu jedoch klinische Daten. Mithilfe dieser Befragung wollen wir aktuell Zystennieren-Patient(inn)en identifizieren, die einer spezifischen Diät folgen (oder dieser in den letzten Jahren gefolgt sind).

Wenn nicht anders angegeben, sollte immer nur eine der Optionen pro Frage ausgewählt werden.

Frage 1: Sind Sie an Zystennieren erkrankt?

Ja nein

Weitere Fragen müssen nur beantwortet werden, wenn Frage 1 mit ja beantwortet wurde.

Frage 2: Wie alt sind Sie?

____ Jahre

Frage 3: Geschlecht?

männlich weiblich divers

Frage 4: Sind Sie dialysepflichtig oder nierentransplantiert?

Ja nein

Frage 5: Fühlen Sie sich gut über Ernährungsempfehlungen informiert?

Ja nein

Frage 6: Welche Quellen nutzen Sie aktuell, um sich über Ernährung zu informieren?

Mehrfachantworten möglich

Fachbroschüren Bücher Internet

Arztgespräche Ernährungsberatung

Andere bitte spezifizieren: _____

Frage 7: Wie klappt die Umsetzung der Ernährungsempfehlungen im täglichen Leben?

Problemlos, mache ich nahezu jeden Tag
keine großen Probleme, ich weiche aber mehrmals im Monat hiervon ab
oft Schwierigkeiten, mehrfach pro Woche kann ich mich nicht daran halten
schaffe ich nur sehr selten oder nie

Frage 8: Folgen Sie aktuell einer spezifischen Diät / Ernährung?

Ja nein (nein ankreuzen, falls Sie normale Vollkost essen)

Falls ja, welche Diätform / Ernährung (Mehrfachantworten möglich)?

Ketogene Diät	Atkins Diät	LowCarb
Kalorienreduktion (im Rahmen eines spezifischen Programms, z.B. OPTIFAST)		
Intermittierendes Fasten (z.B. 16+8)		Fasten
Vegan	Vegetarisch	Proteinarm
Kaliumarm	Phosphatarm	

Andere bitte spezifizieren: _____

Seit wann?

_____Jahre _____Monate

Falls Sie Frage 8 mit nein beantwortet haben, bitte Frage 9 beantworten.

Frage 9: Sind Sie in den letzten 5 Jahren einer spezifischen Diät /Ernährung gefolgt?

Ja nein

Falls ja, welche Diätform / Ernährung?

Ketogene Diät	Atkins Diät	LowCarb
Kalorienreduktion (im Rahmen eines spezifischen Programms, z.B. OPTIFAST)		
Intermittierendes Fasten (z.B. 16+8)		Fasten
Vegan	Vegetarisch	Proteinarm
Kaliumarm	Phosphatarm	

Andere bitte spezifizieren: _____

Über welchen Zeitraum?

_____Jahre _____Monate

Frage 10: Sollte aus Ihrer Sicht mehr Forschung zur Ernährung bei ADPKD durchgeführt werden?

Ja nein

Frage 11: In welchem Bereich der Forschung zu ADPKD besteht aus Ihrer Sicht momentan der größte Bedarf an neuen Studien?

Prüfung der Wirksamkeit neuer Medikamente
Prüfung der Wirksamkeit spezifischer Diät / Ernährung
Beides von gleicher Bedeutung

Frage 12: Stellen Sie sich vor eine Studie zur Untersuchung einer spezifischen Diät / Ernährung wird begonnen (z.B. ketogene Diät oder intermittierendes Fasten). Hätten Sie Interesse an einer Teilnahme?

Ja nein

Falls ja, für welchen Zeitraum wären Sie bereit Ihre Ernährung unter Anleitung / Beratung umzustellen, um eine Untersuchung der Wirksamkeit in der Behandlung der ADPKD zu ermöglichen?

< 1 Monat
1-3 Monate
3-6 Monate
6-12 Monate
12-24 Monate

IV. Questionnaire about ketogenic dietary interventions in ADPKD patients

1

Weimbs Laboratory
Molecular, Cellular, and Developmental Biology
University of California, Santa Barbara

UC SANTA BARBARA
Office of Research

Weimbs Laboratory
Department of Molecular, Cellular and Developmental Biology
University of California Santa Barbara
Principal Investigator: Prof Thomas Weimbs

Questionnaire

Experience of people with ADPKD with ketogenic diets – Implementation and effects

Date: _____

Participant number: _____

Interviewer: _____

For privacy reasons, please do not write your name on any information you provide us!

Introduction

At first, we thank you for choosing to participate in this research study.

As a reminder, you may stop your participation in the research at any time and you have the right to review, remove or modify your information provided if you do not agree with it anymore.

Design of the questionnaire

This questionnaire is not a test. It is not about right or wrong. It is designed to get as much relevant information as possible about your life with ADPKD trying a ketogenic diet. This questionnaire has three parts:

Part I: General information about you and your ADPKD diagnosis

Part II: Questions on personal observations and effects of the ketogenic diet (including Intermittent fasting and Caloric restriction)

Part III: Questions on the feasibility of your diet

How to fill out this Questionnaire

This questionnaire is designed as an open guideline for an accompanying phone or video Interview. In this interview you will go over the questionnaire together with the interviewer who will take care of filling it out for you. We sent this questionnaire to you ahead of the interview so that you can go through the questions in advance and prepare yourself if you like. ***If you fill out as many questions as you can ahead of time it will make the interview much faster.*** It is important that you fully understand every question before answering it. Therefore, please feel free to ask the interviewer for clarification at any time.

Prof. Thomas Weimbs, PhD	Email: weimbs@ucsb.edu
Sebastian Strubl, MD	Email: strubl@ucsb.edu Phone: (805) 4553852

The interview itself will take you about 30 minutes (maximum 1 hour). If you do not wish to answer any of the questions just let the interviewer know. The interview may lead to follow-up questions that are not directly covered by the questionnaire. In this case, the data would be added by the interviewer unless you do not want to include it. If you do not want to participate in an interview it is also possible just to answer the questionnaire on your own and sent it back to us.

The questions are in one of the following formats. Depending on the question format you may...

- ☐ Give your answer as free text or a bullet list in a certain order. In this case you may check as many bullet points as you wish.
- ☐ Describe a frequency like daily, weekly, monthly
- ☐ Give a scale rating e.g. from 0-10

Last, but not least, we kindly ask you to answer the questions as accurately as possible using your memories or any notes you may have taken at the time.

After completion of the Interview

For your privacy, your name will be replaced with a number on all notes that have been taken by the interviewer and will not be included at any time. All data will be stored safely. Additional information and data can be sent to our research team by US mail to the following address:

Attn: Sebastian Strubl
Department of Molecular, Cellular & Developmental Biology
University of California Santa Barbara
Mail Code 9625
Santa Barbara, California 93106

Part I: General Information

1. How old are you?

2. Gender

☐ Female

☐ Male

☐ Other: _____

3. For how many years have you known to have ADPKD?

4. Are you undergoing dialysis treatment or have received kidney transplantation?

☐ YES (Please check below)

☐ NO

☐ Peritoneal dialysis

☐ Hemodialysis

☐ Kidney transplant

5. Are you diagnosed with any of the following ADPKD associated disorders?

☐ YES (Please check below)

☐ NO

☐ Hypertension (high blood pressure)

☐ Pancreas cysts

☐ Liver cysts

☐ Kidney stones

☐ Intracranial aneurysm

☐ Heart valve abnormality/defect

☐ Other (please specify): _____

6. Do you have any other preexisting diseases? If so, please specify

☐ Heart and lung disease (e.g. congestive heart failure, COPD): _____

☐ Vascular disease (e.g. cardiovascular or peripheral vascular disease): _____

☐ Immune disease (e.g. Bowel disease, Rheumatoid arthritis): _____

☐ Endocrinological diseases (e.g. Diabetes, Hyperthyroidism): _____

☐ Other (please specify): _____

7. Have you ever tried any treatment or life style change for ADPKD?

☐ YES

☐ NO

☐ Tolvaptan

☐ Blood pressure control

☐ Limiting salt intake (<2g per day)

☐ Sufficient fluid intake (>3 liters/102 ounces per day)

☐ Increase of physical activity

☐ Dietary changes. Please specify: _____

☐ Other: _____

8. Do other members of your family suffer from ADPKD? If so, please check below if anyone of them is on dialysis or has undergone kidney transplant?

☐ YES (Please check below)

☐ NO

☐ None

☐ Peritoneal dialysis

☐ Hemodialysis

☐ Kidney transplant

9. Please rate your overall personal feeling concerning your health situation at this moment. Tick box and circle the intensity on the scale.

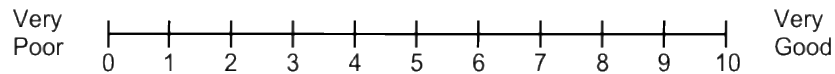
☐ Very poor ("I'm struggling with daily life")

☐ Poor ("Could be better")

☐ Neutral ("I can not complain")

☐ Overall good ("Daily life is mostly not a big problem")

☐ Very good ("I feel great. I'm not compromised at all")



Part II: Questions on personal observations and effects of the ketogenic dietary intake

Before your diet (Ketogenic diet, Intermittent Fasting, Caloric Restriction)

1. What kind of diet have you done or are you currently executing?

- ☐ Ketogenic diet
- ☐ Intermittent fasting
- ☐ Caloric restriction

In all further questions we will refer to "your/my diet" as the diet you have been on or you are currently executing as stated in question 1

2. Have you had any recurrent health issues due to ADPKD? If so, please tick/list those along with their frequency (daily, weekly, monthly) and intensity (using the scale) below.

(Example: "☐ Flank pain

daily, 6")

☐ YES (Please check below)

☐ NO

☐ Flank or back pain/discomfort: _____ (frequency, intensity)

☐ Fatigue: _____ (frequency, intensity)

☐ Diarrhea: _____ (frequency, intensity)

☐ Constipation _____ (frequency, intensity)

☐ Head ache: _____ (frequency, intensity)

☐ Dizziness: _____ (frequency, intensity)

☐ Nausea: _____ (frequency, intensity)

☐ Anxiousness: _____ (frequency, intensity)

☐ Feeling of fullness in your abdomen: _____ (frequency, intensity)

☐ Blood in urine: _____ (frequency, intensity)

☐ Acid reflux _____ (frequency, intensity)

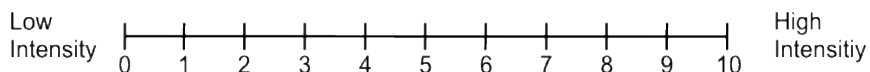
☐ Kidney/cyst infection: _____ (frequency, intensity)

☐ Bladder infection _____ (frequency, intensity)

☐ Gout attacks: _____ (frequency, intensity)

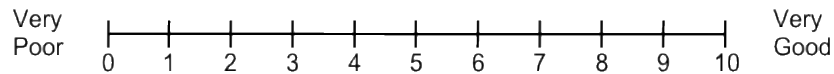
☐ Depression: _____ (frequency, intensity)

☐ Other (please specify): _____



3. Please rate your overall personal feeling concerning your health situation **before** your diet. Additionally, circle your answer on the scale: 0 very poor - 10 very good.

- ☐ Very poor ("I was struggling with daily life")
☐ Poor ("Could have been better")
☐ Neutral ("I could not complain")
☐ overall good ("Daily life was mostly not a big problem")
☐ Very good ("I felt great. I was not compromised at all")



During/after your diet

1. How did you find out about your diet

- ☐ Doctor/ Nephrologist
☐ Nutritionist
☐ Books and scientific publications
☐ Internet
☐ Social media
☐ Other (please specify): _____

2. Why are /were you on your diet?

- ☐ ADPKD
☐ Weight loss
☐ Other (please specify): _____

3. Have you changed/started anything else beside your diet (e.g. supplements, change in water intake)?

☐ YES (Please specify below) ☐ NO

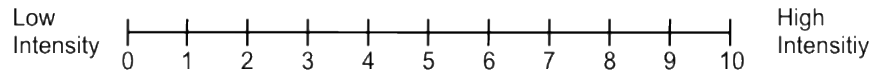
4. When you think back to the time when you started your diet did you have any **new** health issues? If so, how soon did they start and did they persist? Please tick/list along with their frequency (daily, weekly, monthly) and intensity (using the scale) below.

(Example: "☺ head ache: Start within 1 week , daily, 6")

☐ YES (Please check below)

☐ NO

- | | | |
|--|-------|------------------------|
| <input type="radio"/> Head ache: | _____ | (frequency, intensity) |
| <input type="radio"/> Nausea/Vomitting: | _____ | (frequency, intensity) |
| <input type="radio"/> Fatigue: | _____ | (frequency, intensity) |
| <input type="radio"/> Foggy brain: | _____ | (frequency, intensity) |
| <input type="radio"/> Stomach ache: | _____ | (frequency, intensity) |
| <input type="radio"/> Other Pain (Please specify): | _____ | (frequency, intensity) |
| <input type="radio"/> Diarrhea: | _____ | (frequency, intensity) |
| <input type="radio"/> Constipation: | _____ | (frequency, intensity) |
| <input type="radio"/> Bad breath: | _____ | (frequency, intensity) |
| <input type="radio"/> Excessive thirst: | _____ | (frequency, intensity) |
| <input type="radio"/> Hunger: | _____ | (frequency, intensity) |
| <input type="radio"/> Difficulty concentrating | _____ | (frequency, intensity) |
| <input type="radio"/> Difficulty sleeping | _____ | (frequency, intensity) |
| <input type="radio"/> Anxiety: | _____ | (frequency, intensity) |
| <input type="radio"/> Feeling cold: | _____ | (frequency, intensity) |
| <input type="radio"/> "Keto flu": | _____ | (frequency, intensity) |
| <input type="radio"/> Other (Please specify): | _____ | |



5. Did these issues go away over time?

- ☐ I had no new health issues
- ☐ All new issues went away within a week
- ☐ All new issues went away within a month
- ☐ Most new issues were gone within a month
- ☐ Most new issues remained during the time I was on the ketogenic diet

6. If any **new** health issues persisted during the time on your diet please check below

- ☐ Head ache: _____ (frequency, intensity)
- ☐ Nausea/Vomitting: _____ (frequency, intensity)
- ☐ Fatigue: _____ (frequency, intensity)
- ☐ Foggy brain: _____ (frequency, intensity)
- ☐ Stomach ache: _____ (frequency, intensity)
- ☐ Other Pain (Please specify): _____ (frequency, intensity)
- ☐ Diarrhea: _____ (frequency, intensity)
- ☐ Constipation: _____ (frequency, intensity)
- ☐ Bad breath: _____ (frequency, intensity)
- ☐ Excessive thirst: _____ (frequency, intensity)
- ☐ Hunger: _____ (frequency, intensity)
- ☐ Difficulty concentrating _____ (frequency, intensity)
- ☐ Difficulty sleeping _____ (frequency, intensity)
- ☐ Anxiety: _____ (frequency, intensity)
- ☐ Feeling cold: _____ (frequency, intensity)
- ☐ "Keto flu": _____ (frequency, intensity)
- ☐ Other (Please specify): _____

7. Did you experience any weight loss after starting your diet? Please check box and specify your starting weight and your average weight loss

- ☐ No, not at all
- ☐ Yes (please describe below)
 - ☐ It leveled off after a few weeks
 - ☐ I'm still benefitting from continued weight loss
 - ☐ I'm still struggling with continued weight loss

Starting weight before diet: _____ lbs
 Average weight loss: _____ lbs

Please describe if you can recall details about your weight loss (E.g.: When did it start? Did the weight come back?)

8. Did you experience any change in water consumption after starting your diet?

- ☐ No, my water consumption has not changed
- ☐ Yes, I automatically consumed/needed more water
- ☐ Yes, I consumed more water because it is recommended when starting this diet

Water consumption **before** my diet: _____ liter/ounces per day
 Water consumptions **during** my diet: _____ liter/ounces per day

9. Have any **old** health issues (mentioned above in Part 2, Question 1) changed after starting your diet? If so, please tick/list those along with their changed (improved or worsened) frequency (daily, weekly monthly) and intensity (using the scale).

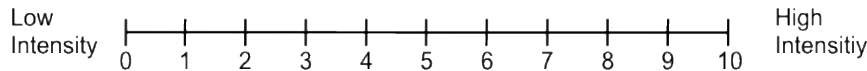
(Example: "⊗ Fatigue:

⊗ Improved O Worsened: monthly, 2)

O YES (Please check below)

O NO

O Flank or back pain/discomfort:	O Improved O Worsened: _____ (frequency, intensity)
O Fatigue:	O Improved O Worsened: _____ (frequency, intensity)
O Diarrhea:	O Improved O Worsened: _____ (frequency, intensity)
O Constipation	O Improved O Worsened: _____ (frequency, intensity)
O Head ache:	O Improved O Worsened: _____ (frequency, intensity)
O Dizziness:	O Improved O Worsened: _____ (frequency, intensity)
O Nausea:	O Improved O Worsened: _____ (frequency, intensity)
O Anxiousness:	O Improved O Worsened: _____ (frequency, intensity)
O Feeling of fullness in your abdomen:	O Improved O Worsened: _____ (frequency, intensity)
O Blood in urine:	O Improved O Worsened: _____ (frequency, intensity)
O Acid reflux	O Improved O Worsened: _____ (frequency, intensity)
O Kidney/cyst infection:	O Improved O Worsened: _____ (frequency, intensity)
O Bladder infection	O Improved O Worsened: _____ (frequency, intensity)
O Gout attacks:	O Improved O Worsened: _____ (frequency, intensity)
O Depression:	O Improved O Worsened: _____ (frequency, intensity)
O Other (please specify): _____	O Improved O Worsened: _____ (frequency, intensity)



10. Did you have any changes in medication within the first year on your diet? If so, check below and if possible specify the change (e.g. dose, frequency)

O YES (please specify below)

O NO

O Antihypertensive drugs:	O Increased O Decreased: _____ (dose, frequency)
O Diabetes drugs:	O Increased O Decreased: _____ (dose, frequency)
O Diuretics:	O Increased O Decreased: _____ (dose, frequency)
O Pain killer:	O Increased O Decreased: _____ (dose, frequency)
O Other medication:	O Increased O Decreased: _____ (dose, frequency)

11. Do you feel that your diet improved your ADPKD symptoms?

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neutral
- ☐ Somewhat disagree
- ☐ Strongly disagree

12. Have you found any changes in health data you are measuring (e.g. blood pressure, blood glucose). If so, please describe below.

- ☐ YES (Please check below) ☐ NO ☐ I have not measured anything

- ☐ Blood pressure
- ☐ Blood keto level
- ☐ Blood glucose level
- ☐ Other (please specify): _____

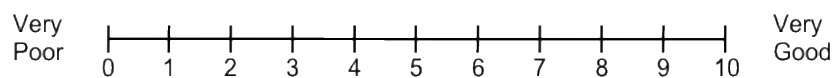
13. Has your physician found any changes in medical examination since you started your diet? If so, please tick/list below and specify if possible.

- ☐ YES (Please check below) ☐ NO

- ☐ Blood pressure (Please specify): _____
- ☐ Blood parameter (Please specify): _____
- ☐ GFR (Please specify): _____
- ☐ Creatinine (Please specify): _____
- ☐ Kidney volume/size (Sonography/MRI): _____
- ☐ Kidney length/size (Sonography/MRI): _____
- ☐ Other (please specify): _____

14. Please rate your overall personal feeling concerning your health situation during your diet. Tick box and circle intensity on the scale below

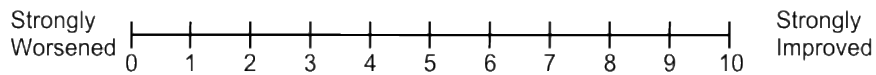
- ☐ Very poor ("I was struggling with daily life")
- ☐ Poor ("Could have been better")
- ☐ Neutral ("I could not complain")
- ☐ Overall good ("Daily life was mostly not a big problem")
- ☐ Very good ("I felt great. I was not compromised at all")



11

15. What impact (if any) did your diet have on your health and well-being? Use the scale below. Tick box and circle effect on scale

- ☐ Strongly worsened
- ☐ Somewhat worsened
- ☐ Stayed about the same
- ☐ Somewhat improved
- ☐ Strongly improved



16. Have you experienced any other changes or effects upon your diet? If so, please list it below

17. During your experience with your diet, have you or your doctor noticed any changes that raised a safety concern?

- ☐ YES ☐ NO

If so, please explain:

18. Do you agree with self reporting health care information obtained from you, your primary care physician or nephrologist?

- ☐ YES (please specify your self report below) ☐ NO

- ☐ Blood tests (e.g. Creatinine, eGFR, Vitamin D, PTH, EPO)
- ☐ Urine tests (Proteins, Sediment, Glucose, Ketone bodies, crystals, citrate, pH)
- ☐ Blood pressure measurements/trends
- ☐ Imaging diagnostics (ultrasound, MRI, CT)

Please deidentify all personal information (e.g. Name, birth date) on the health care information by blackening it out and replace it with your participant number as stated on the first page of this questionnaire. Then, please send it to the following address:

Attn: Sebastian Strubl
 Department of Molecular, Cellular & Developmental Biology
 University of California Santa Barbara
 Mail Code 9625
 Santa Barbara, California 93106

Weimbs Laboratory, Department of Molecular, Cellular & Developmental Biology,
 University of California Santa Barbara

Part III: Feasibility of your diet

1. Are you currently on your diet? If not, please describe below why you have stopped
☐ YES ☐ NO (please check below)

☐ Due to side effects of my diet
☐ Due to other health issues (please specify): _____
☐ Due to the practical difficulty in executing my diet
☐ Other: _____

2. For how long have you been on your diet?

Years/months: _____

3. Have you had any breaks in between your diet?
☐ YES (please check below) ☐ NO

☐ Due to side effects of my diet
☐ Due to other health issues (please specify): _____
☐ Due to the practical difficulty in executing my diet
☐ Other: _____

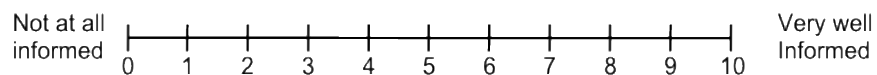
4. Please describe your diet in detail, how you found it and why you chose it?

5. What resources do you use to keep yourself informed about nutrition and diets?

- ☐ Books
- ☐ Internet (websites)
- ☐ Social media
- ☐ Nutritionist
- ☐ Physician
- ☐ Scientific publications
- ☐ Talking with friends or family
- ☐ Other (please specify): _____

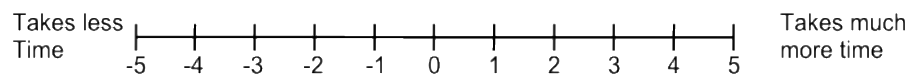
6. Do you feel well informed about nutrition and diets? Please tick box and circle intensity on scale

- ☐ Not at all informed
- ☐ Poorly informed
- ☐ Neutral
- ☐ Well informed
- ☐ Very well informed



7. Does it take more time for you to prepare your dietary food than your regular food? Please tick box and circle on scale

- ☐ It takes less time
- ☐ It takes about the same time as a regular diet
- ☐ It takes a little more time
- ☐ It takes much more time



8. Have you tried other diets? If so please check below
☐ YES ☐ NO

☐ Atkins diet
☐ Calorie restriction
☐ Low-Carb diet
☐ Glycemic index diet
☐ Low-Fat diet
☐ Intermittent fasting
☐ Vegetarian diet
☐ Vegan diet
☐ Other (Please specify): _____

9. Were/are you taking any nutritional or ketogenic supplements? If so, please list it below
☐ YES ☐ NO

10. Are you performing any regular examination yourself regarding your diet? If so, please tick boxes when it applies

☐ YES ☐ NO

☐ Blood pressure
☐ Blood keto level
☐ Blood glucose level
☐ Urine keto level
☐ Other (please specify): _____

11. Are you doing your diet under supervision of a doctor or nephrologist? If so, please check examinations methods below and specify frequency

(Example: "☺ Blood work: Once a month)

☐ YES ☐ NO

☐ Blood work: _____ (frequency)
☐ Blood keto level: _____ (frequency)
☐ Urine: _____ (frequency)
☐ Urine keto level: _____ (frequency)
☐ Blood pressure: _____ (frequency)
☐ Sonography: _____ (frequency)
☐ MRI/CT scan: _____ (frequency)
☐ Other (please specify): _____ (frequency)

12. How was your doctor/nephrologist first thinking of the idea of trying your diet

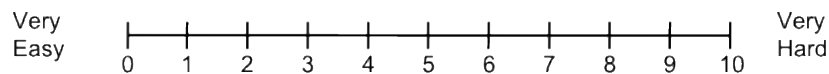
- ☐ He/she tried to hold me back
- ☐ He/she was skeptical but supported me
- ☐ He/she was curious and supported me
- ☐ He/she actually suggested trying my diet

13. How is your doctor/nephrologist thinking after seeing your experience with your diet on your ADPKD?

- ☐ He/she is not convinced at all
- ☐ He/she is skeptical but still supporting me
- ☐ He/she is convinced and suggesting the diet to other ADPKD patients
- ☐ I don't know what he/she thinks

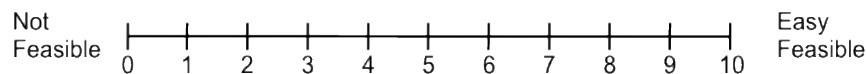
14. How was the switch from normal nutrition to your diet for you? Additionally, circle your answer on the scale: 0 very easy - 10 very hard.

- ☐ It was not a problem at all
- ☐ It took some time but it was manageable
- ☐ It was a difficult switch but I can manage now
- ☐ It was very hard and I'm still struggling with it



15. Rate the overall feasibility of your dietary approach in daily life. Tick box and circle feasibility on scale

- ☐ No problem at all, doing the diet every single day
- ☐ No real problem but sometimes I skip it several times a month
- ☐ Difficult, I skip it several times a week
- ☐ Very difficult, I can barely execute the diet



16

16. Please list your personal problems concerning the feasibility of your diet in order (1. Biggest problem, 10. Less problem)

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

17. Please list all things that helped you and improved your execution of your diet in order (1. Biggest help, 10. Less help)

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

18. Do you **personally** know people with ADPKD (e.g. a family member or personal friend) who had a negative experience with your diet? If so, how many?

☐ YES: _____ ☐ NO

19. Do you feel that your diet is safe for people with ADPKD?

- ☐ Strongly agree
☐ Somewhat agree
☐ Neutral
☐ Somewhat disagree
☐ Strongly disagree

20. Do you feel that your diet is easy to do for people with ADPKD?

- ☐ Strongly agree
☐ Somewhat agree
☐ Neutral
☐ Somewhat disagree
☐ Strongly disagree

21. Would you recommend the your diet to a friend or family member with ADPKD?

- ☐ Strongly agree
- ☐ Somewhat agree
- ☐ Neutral
- ☐ Somewhat disagree
- ☐ Strongly disagree

22. Do you have any further ideas and suggestions that would improve the feasibility of your diet?

Conclusion

We want to thank you again for participating in this research study and for taking time to answer this questionnaire. We will provide you with a copy of this questionnaire with the information you shared with us.

As a reminder you may stop your participation in this research at any time even after handing in any information about you. At any time you have the right to review the information you have provided and you can ask to modify or remove information if you do not agree with it anymore.

If you have any questions you are welcome to contact the members of our research team (Thomas Weimbs, Sebastian Strubl) at anytime.

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This Questionnaire has been reviewed and approved by the institutional review board (IRB) of the University of California Santa Barbara, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about the IRB, please contact

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